Reference: FOI.ICB-2627/122

Subject: Endometriosis and Adenomyosis Services and Pathways

I can confirm that the ICB does hold some of the information requested; please see responses below:

<table>
<tr><th>QUESTION</th><th>RESPONSE</th></tr>
<tr><td>1. Please provide the number of patients recorded with a diagnosis of endometriosis within datasets available to the ICB, by financial year, for each of the last five financial years. If exact figures are not held, please provide any estimates available.</td><td>These figures are derived from Admitted Patient Care (APC), Outpatient (OP) and Emergency Care (ECDS) datasets. A diagnosis of endometriosis was identified using ICD-10 codes N80.0–N80.9 (APC/OP) and SNOMED CT codes 109861009, 237117005, 1367678009, 850950361000119102, 314049009, 129103003 and 9563009 (ECDS). Responses are based on a diagnosis recorded in any diagnosis position where it was relevant to the reason for attendance. Patients are counted once per financial year, regardless of the number of episodes or attendances recorded.

<table><tr><td>Financial Year</td><td>Endometriosis_Patients</td></tr><tr><td>2021/22</td><td>1,062</td></tr><tr><td>2022/23</td><td>1,304</td></tr><tr><td>2023/24</td><td>1,449</td></tr><tr><td>2024/25</td><td>1,779</td></tr><tr><td>2025/26</td><td>2,212</td></tr></table></td></tr>
<tr><td>2. Please provide the number of patients recorded with a diagnosis of adenomyosis within datasets available to the ICB, by financial year, for each of the last five financial years. If exact figures are not held, please provide any estimates available.</td><td>These figures are derived from Admitted Patient Care (APC), Outpatient (OP) and Emergency Care (ECDS) datasets. A diagnosis of adenomyosis was identified using ICD-10 code N80.0 (APC/OP) and SNOMED CT code 784314006 (ECDS). Please note that standard ICD-10 does not hold a code specific to adenomyosis; N80.0 ("endometriosis of uterus") is used for both endometriosis of</td></tr>
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<table>
<tr><td></td><td>the uterus and adenomyosis, so APC/OP figures may include some overlap with endometriosis of the uterus. SNOMED CT, used for the ECDS dataset, does hold a distinct adenomyosis concept. Responses are based on a diagnosis recorded in any diagnosis position where it was relevant to the reason for attendance. Patients are counted once per financial year, regardless of the number of episodes or attendances recorded.

<table>
<tr><td>Financial Year</td><td>Adenomyosis_Patients</td></tr>
<tr><td>2021/22</td><td>234</td></tr>
<tr><td>2022/23</td><td>269</td></tr>
<tr><td>2023/24</td><td>341</td></tr>
<tr><td>2024/25</td><td>435</td></tr>
<tr><td>2025/26</td><td>579</td></tr>
</table></td></tr>
<tr><td>3. Please provide the number of referrals for suspected endometriosis received within the ICB area, by financial year, for each of the last five financial years.</td><td>The ICB does not hold this information. We advise you to contact the trusts directly, as follows:

North Bristol NHS Trust (NBT): https://www.nbt.nhs.uk/about-us/information-governance/freedom-information/request-information

University Hospitals Bristol and Weston NHS Foundation Trust (UHBW): https://www.uhbw.nhs.uk/p/how-we-use-your-data/freedom-of-information-foi-requests</td></tr>
<tr><td>4. Please provide the average waiting time from referral to a first specialist gynaecology appointment for patients with suspected endometriosis during the most recent complete financial year. If available, please also provide data for the previous four financial years.</td><td>Average waiting times at the speciality level can be found here for all NHS commissioned providers in England Home - My Planned Care NHS

This data is however at the speciality level and will show average waiting time for a first appointment in a gynaecology service. It does not provide information specific to the average waiting times of the sub-set of patients that have been referred with suspected</td></tr>
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	endometriosis. Data at this level is not available in the ICB. A provider of endometriosis services may be able to offer an average wait time for appointments for patients with suspected endometriosis.
5. Please provide the average waiting time from referral to diagnostic laparoscopy for suspected endometriosis, where recorded. If this information is not held centrally, please provide any available waiting-time data relating to diagnostic investigations for suspected endometriosis.	As above. Waiting time data available nationally or within the ICB data sets does not enable identification of waiting times for diagnostics or diagnostic procedures for specific conditions or suspected conditions. The ICB are therefore unable to provide the average waiting time from referral to diagnostic laparoscopy for suspected endometriosis.
6. Please provide the names of the specialist endometriosis centres and providers to which patients within the ICB area are routinely referred.	Specialist services in BNSSG include: • Southmead Hospital (North Bristol NHS Trust), • St Michael's Hospital, and • Weston General Hospital (United Hospitals Bristol and Weston NHS Foundation Trust). Provision comes under Gynaecology services and is for severe, persistent or recurrent symptoms of endometriosis, for pelvic signs of endometriosis or if initial management is ineffective, not tolerated or is contraindicated. Both Southmead Hospital and St Michael's Hospital are BSGE (British Society of Gynaecological Endoscopy) accredited endometriosis centres providing gynaecologists, specialist nurse, colorectal surgeon, urologist and pain specialist all with expertise in endometriosis and is where patient with suspected or confirmed deep endometriosis involving the bowel, bladder or ureter, endometrioma (≥ 3cm) or extra pelvic endometriosis e.g. thoracic endometriosis are referred to. For paediatric and adolescent patients (aged 17 and under)

	patients are referred into the Paediatric and Adolescent Gynaecology Service at St Michael's Hospital (UHBW). All referral information is available here Endometriosis (Remedy BNSSG ICB)
7. Please provide copies of any current care pathways, service specifications, policies or guidance documents relating to endometriosis.	Resource and guidance documents are available here: Endometriosis (Remedy BNSSG ICB) Please contact providers of these services for information on specific care pathways. See question 3 for contact details.
8. Please provide details of any digital tools, mobile applications, websites or self-management resources that are currently recommended, commissioned or signposted by the ICB for patients with endometriosis or adenomyosis.	The resources section in our Remedy pages Endometriosis (Remedy BNSSG ICB) provides links for organisations that offer patient support. ***"Patient support:*** *Endometriosis UK is a charity that provides free information and support to those with endometriosis. There is a local Bristol support group. (https://www.endometriosis-uk.org)* *Pelvic Pain Support Network is an organisation that provides support, information and advocacy for those with pelvic pain, their families and carers. (https://www.pelvicpain.org.uk)"* Further information of use, including direct links to Endometriosis UK and additional resources is available here: Persistent Pelvic Pain (women) (Remedy BNSSG ICB) The ICB also provides a local women's health training hub for staff Women's Health - BNSSG Training Hub. The training hub includes a link to the Women's Health Event dedicated to Endometriosis held in 2024.

	There is a separate hub for the public - Women's Health - Well Aware, which also serves the purpose of increasing awareness for staff.. The public resource includes information on endometriosis on the Period Problems - Well Aware page. Other useful information, links can be found here Women's health - BNSSG Healthier Together
9. Please provide details of any funding, investment programmes, service development initiatives or allocated budgets specifically intended to improve endometriosis services during each of the last three financial years.	No specific investment programmes or service development initiatives have been directed by the ICB for specifically endometriosis services in the Acute Trusts in the last three financial years. Financial allocations to the NHS Trusts do not specify budget allocation at speciality or sub speciality level.
10. Please provide details of any funding, investment programmes, service development initiatives or allocated budgets specifically intended to improve adenomyosis services during each of the last three financial years.	No specific investment programmes or service development initiates have been directed by the ICB for specifically adenomyosis services in the Acute Trusts the last three financial years. Financial allocations to the NHS Trusts do not specify budget allocation at speciality or sub speciality level.
11. Please provide copies of any service reviews, audits, needs assessments, gap analyses or evaluation reports relating to endometriosis or adenomyosis that have been undertaken or commissioned within the last five years.	The BNSSG Gynaecology Healthcare Needs Assessment is underway, led by Bristol City Council and the ICB. It evaluates local population needs to improve service design and includes endometriosis prevalence, need related to endometriosis and current service provision, care pathways, and current service experiences. This builds on the 2023 publication Women's Health in Bristol that provides information related to endometriosis in BNSSG. NHS Bristol, North Somerset and South Gloucestershire ICB Research Capability Funding is however supporting a research piece; *"Exploring the understanding and experiences of*

	gynaecological issues (including endometriosis) for under-served women from ethnically minoritised communities" Exploring the understanding and experiences of gynaecological issues (including endometriosis) for under-served women from ethnically minoritised communities. This will include interactions with healthcare professionals while accessing care - BNSSG Healthier Together
12. Please provide the number of specialist endometriosis services currently commissioned by the ICB and the nature of those services.	See answer to question 6.
13. Please provide copies of any documents, reports, meeting minutes, audits or analyses that identify factors contributing to delays in the diagnosis of endometriosis.	The ICB does not have any internal documents, reports, meeting minutes, audits or analyses that identify factors contributing to delays in the diagnosis of endometriosis. The 2023 publication Women's Health in Bristol does offer a small amount of information related to endometriosis in BNSSG, but reflects the England average diagnosis time rather than BNSSG specific. It recognises that there is limited data available on the prevalence of gynaecological conditions in Bristol, which triggered the commencement of the BNSSG Gynaecology Healthcare Needs Assessment in 2025.
14. Please provide copies of any documents, reports, meeting minutes, audits or analyses relating to barriers to the timely diagnosis of endometriosis or adenomyosis.	The ICB does not have any documents, reports, meeting minutes, audits or analyses relating to barriers to the timely diagnosis of endometriosis or adenomyosis.
15. Please provide copies of any referral templates, referral guidance documents, triage criteria or audits relating to referrals for suspected endometriosis.	Referral guidance is available here: Endometriosis (Remedy BNSSG ICB). BNSSG ICB has a generic referral template, please find enclosed.

	icb-bnssg-standard-referral-form-template The ICB does not hold audits relating to referrals for suspected endometriosis. Further information may be held by the providers. See question 3 for contact details.
16. Please provide copies of any standardised symptom assessment tools, questionnaires or patient-reported outcome measures used across commissioned services for patients with suspected endometriosis.	The ICB does not hold this information. This should be requested from providers of these services. See question 3 for contact details.
17. Please provide copies of any patient information forms, questionnaires, checklists or guidance documents that set out the information routinely requested from patients prior to their first specialist appointment for suspected endometriosis	The ICB does not hold this information. This should be requested from providers of these services. See question 3 for contact details.

The information provided in this response is accurate as of 17 July 2026 and has been approved for release by Helena Fuller, Deputy Director of Business, Strategy and Planning for NHS Bristol, North Somerset and South Gloucestershire ICB.

Organisation Name
Organisation Full Address (stacked)

Organisation Telephone Number
Organisation E-mail Address

Routine ☐

Urgent ☐

Practice Information			
Referring Clinician:	Free Text Prompt	**Referral decision date:**	Long date letter merged

Patient Details					
NHS Number:	NHS Number			**Name:**	Full Name
D.O.B:	Date of Birth	**Age:**	Age	**Address:**	Home Full Address (stacked)
Gender	Gender(full)				
Ethnicity	Ethnic Origin				
Tel:	Patient Home Telephone				
Other:	Patient Mobile Telephone				

Please consider referral guidance in Remedy prior to referral or use advice and guidance services where available.

Key Dataset	
Primary Reason for Referral:	
Specialty:	**Provider Preference:**
Communication needs and health inequalities: e.g., interpreter required (please state language), hearing or visual impairment, mental or physical disability, learning difficulties, homelessness, deprivation, digital exclusion, etc. Single Code Entry: Learning disability Single Code Entry: Autism Single Code Entry: Schizophrenia...	
If this is a referral for a condition which is not routinely funded please mark relevant box below **(Please click here to view the funding policies)** ☐ **PA** (Please see advocacy section on the E-Referral System for funding reference number) ☐ **CBA** (The referral outlines how the patient meets the criteria set out in the policy) ☐ **IFR** (Funding confirmation letter enclosed)	

Has advice and guidance been obtained **(See REMEDY for more information regarding the Advice and Guidance service)**	**Yes** ☐	**If yes, please attach the outcome**
	No ☐	**If no, then please consider if this may be appropriate**

Dear Colleague,

Please enter your referral letter here. Secondary care colleagues kindly request that you do not just enter 'see consultations below'.

Yours faithfully,

Consultations
Consultations

Problems:
Problems

Medication:
Medication

Allergies:
Allergies

Investigations:
Investigations

Most recent health status info:

HbA1c
Height
Weight
BMI
Blood Pressure
Smoking
Alcohol Consumption

Enclosed information/correspondence/proformas (if applicable):